Seeking Pathways to a Coordinated System of Health and Human Services for High-risk Urban Children and Families: The Rochester, New York Experience

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Abstract. *The Rochester, New York community has undergone major changes over the past 20 years. Like many other industrial areas, it has seen an erosion of its manufacturing base and a flight of employment opportunities and population from the city to the suburbs. While commonly misperceived as an affluent, white-collar community, in reality there are many families, particularly within the city of Rochester, that are afflicted by some of the most devastating health and social problems facing the United States today.[1] It was against this backdrop that, in 1991, an ongoing effort was begun to develop a system of coordinated health and human services to more effectively address the needs of Rochester's children and families. As a first step, a study was conducted to obtain a detailed picture of the current service system in Rochester; lay out a series of recommendations to improve collaboration and communication; and foster coordinated and integrated services for high-risk youth and families in the community. Key indicators of child and family health were collected, collated, and analyzed, and extensive interviews were conducted with human-service and medical providers, government officials, education professionals, and parents. This paper describes the process that was used in the study and the recommendations that were included in the final report, which is intended to create a framework for the creation of a comprehensive, needs-based health care system for impoverished and at-risk children and families, including the effective integration of health services into the human service network.*

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Overview

Children and families who live in poverty or are otherwise at high risk face many obstacles in the current health care system. One of the most difficult obstacles is the manner in which child health has historically been viewed. The traditional view is exclusively centered on medical interventions, but the health of children living in poverty is inextricably intertwined with their socioeconomic circumstances and requires organized interventions extending far beyond the parameters of traditional medicine. Although there has been substantial progress in preventing or ameliorating the effects of many physical health problems of children, little progress has been made in addressing problems that stem from the child's life circumstances. Families facing the many issues that accompany poverty need to have ready access to an array of preventive and supportive health and human services. A growing literature reflects the number of individuals and communities recognizing the shortcomings of the current categorical organization of services and the need for more integrated and coordinated health and human services for children and families.[2–8]

Children growing up in poverty are likely to experience some of the most severe social problems facing our nation today. This fact is true in Rochester, as it is in other parts of the country. To cite just a few examples:

- In 1989, a Children's Defense Fund study ranked Rochester 13th in the nation for the percentage of its children living in poverty.[1] Whereas 14% of the city's children lived in poverty in 1969, growing to 27% by 1979, in 1989 a full 38% lived below the poverty line, more than in New York City and the same as in Newark, New Jersey. Twenty-five percent of white children, 47% of black children, and 55% of Hispanic children in Rochester are living in poverty.
- Between 1970 and 1993, the proportion of elementary-school students in the Rochester City School District who are poor, defined as those who qualify for free or reduced-price lunches, increased by 615%. In 1992, 76% of the district's elementary

students, or 18,000 children, were classified as poor, a 7% increase in just the past 2 years alone (Gannett Rochester Newspapers, Nov. 7, 1993).

- In 1990, 46% of Rochester's families with children had only a single parent present, and 65% of them were living below the poverty level. In 1980, 33% of Rochester families had single parents, as compared to 17% in 1970. Fifty-four percent of white, 71% of black, and 65% of Hispanic families in the city of Rochester are single-parent families.
- Rochester has the highest teenaged pregnancy rate in the state of New York—more than 1600 teen-agers become pregnant annually (150.6/1000 aged 15–17 years).
- Thirty-three percent of all babies born to Rochester residents have mothers who did not complete high school.
- Half of the kindergartners entering the Rochester city schools in the last 5 years arrived with one or more serious problems with vision, hearing, or learning skills.
- One of four children in the early elementary-school grades in Rochester will move at least once during the school year.

In 1990, a new Health Director was appointed for Monroe County, where Rochester is located. This person has a background as Chief of Pediatrics at the city's largest neighborhood health center, and an acute awareness of the need for better integration of services. Later that year, the University of Rochester School of Medicine and Dentistry recruited the then Director of Maternal and Child Health Services for the city of Boston, a member of the faculty of Boston University School of Medicine, to serve as Associate Chairman for Community Affairs in the Department of Pediatrics. He brought to Rochester an understanding of the relationship between community social problems and child health status, and a keen interest in improving the coordination and integration of services to improve child health.

In their initial meetings, the two physicians recognized the opportunity for the Health Department and the Department of Pediatrics at the University to enhance the missions and capabilities of each, and to collaborate and develop new service-delivery

needs. It was immediately recognized that there was a need for a more-comprehensive database about child health status and services in the community. As a first step, the Monroe County Child Health Council, comprised of high-level representatives of health, education, and social service agencies, as well as public officials, was created to serve as a planning and advisory group. This group has met regularly for the past 3 years and has actively participated in the successful pursuit of funding from two sources to begin restructuring services for high-risk children and families.

Identifying Pathways to Coordinated Services

As an initial step toward coordinating and integrating services, the Department of Pediatrics and the Monroe County Health Department received funding in 1992 from the W. T. Grant Foundation to conduct a study entitled, "Identifying Pathways to Integrated and Comprehensive Services for High Risk Youth and Families in Rochester, New York." The project's goals were to:

1. Collect, collate, and analyze key indicators of child and family health in Monroe County and Rochester;
2. Obtain a detailed picture of the current service system in Rochester and make recommendations to improve collaboration and communication and to foster coordinated and integrated services for high-risk youth and families in the community;
3. Sustain existing interest and build support in the local business community, the county and city government, and the health-care community regarding issues of high-risk children and families and the need to coordinate efforts; and
4. Plan reorganized services, that are coordinated and integrated for specific high-risk groups in the community.

Information was gathered and analyzed from three different sources: interviews with public officials and health and human service providers; interviews with selected parents; and the review, collation, and analysis of data collected by the Health Department and other agencies and projects. Key indicators of child

and family health and functioning were investigated, using information from the 1990 census, the Health Department's Community Health Assessment and Nutrition Watch reports, and several other sources. Through the gathering of these data, we have been able to obtain a clearer picture of the health and social status of Monroe County and Rochester children, and have identified a series of annually updated indicators to form a Child Health Report Card for the continuous monitoring of the circumstances of area children. The indicators selected for the Report Card include: 1) socioeconomic data, such as percentages of children living in poverty, living in single-parent families, born to single mothers, and receiving Aid for Families with Dependent Children and Medicaid; 2) infant health data, such as infant mortality, low-birthweight rates, and early prenatal care; 3) teen sexuality, such as pregnancy rates, sexually transmitted disease rates, and percentage reporting sexual activity; 4) school performance indicators; 5) violence indicators, such as the homicide rate, reported cases of child abuse and neglect, and suspensions for fighting and assault; 6) immunization rates; 7) asthma hospitalization rates; 8) lead-poisoning indicators; and 9) participation rates in nutrition support programs such as food stamps, the Special Supplemented Nutrition Program for Women, Infants and Children (WIC), and school breakfast and lunch programs.

Eighty interviews were conducted with local and state elected officials, and providers and administrators from health care, education, social services, and day care agencies. All of the questions were open-ended and sought opinions on the adequacy of services, problems, and solutions to coordinating care for children and families with multiple needs, community priorities, and a variety of other topics. Sixty-two parents also were interviewed while they were waiting at a WIC nutrition program site. Parents were queried about what services they believe are important to families, what types of improvements would be helpful, and a variety of other topics.

Because scientific sampling methods were not used with the interviews, the findings are not representative of all individuals in

the Rochester area. This part of the project, especially the interviews with public officials and health and human services providers, involved significant difficulties both in obtaining and utilizing data. This was so, in part, because many of those interviewed articulated numerous problems but were unable to identify potential solutions. In addition, parents called for services designed to address the whole family's needs in one location, and for a service delivery system designed with the family's circumstances in mind (hours of operation, transportation issues, etc.) instead of for the operational convenience of the agencies. These problems were rarely raised by the service providers, as it is difficult for people at high levels of the service-delivery system to recognize them, especially since the effort to keep an agency alive and operating in the current fiscal climate is often monumental.

Should a locality attempt to pursue a similar project, we would recommend interviewing more individuals serving "on the front lines" of the service-delivery system, as well as those with administrative responsibility; comparing the two groups' perceptions might be illuminating. It also would be useful to structure some survey questions so as to to obtain more quantitative data—our survey instrument was quite qualitative, which made the data difficult to compile and display. Despite these limitations, the results provide many significant insights into the needs of children and families as perceived by a substantial number of local leaders, service providers, and consumers of services in our community. These insights have been widely incorporated into our recommendations.

Designing Model Integrated Services

Members of the Child Health Council believe it is vital that there be ongoing projects and program development to maintain community enthusiasm and interest in systems change. After receiving funding for the study, the Monroe County Health Department, the Department of Pediatrics, and the Child Health Council applied to participate in The Robert Wood Johnson Foundation's

Child Health Initiative. A three-year grant was awarded in July 1993, and a project is being developed in Rochester. The Robert Wood Johnson Foundation has set three major goals for this initiative:

1. Creation of a flexible financing plan, or Child Health Fund, which will pool categorical funding to make programs more responsive to the needs of children and families;
2. Creation of a care coordination model utilizing the increased flexibility allowed by the broadened funding stream;
3. Preparation of an annual Children's Health Status Report, or Child Health Report Card, which will provide a comprehensive description of the health status of the community's children via health indices and other indicators of well-being.

Many service providers and community leaders identified as a problem the sheer number of initiatives underway to address the problems of at-risk families. They said that coordination and communication between the initiatives is imperative to avoid re-creating, within the efforts for change, the duplicative and confusing service system that currently exists. The present authors are creating a formal mechanism for ensuring that the directors of the various programs communicate regularly to share information, ensuring that duplication is not taking place, and identifying areas where initiatives can work together to achieve common goals.

The Effects of Managed Care on the Process

Substantial changes have occurred in the relatively brief time since these efforts began. The virtual reality of increased Medicaid-managed care in New York State, and of national health care reform in the near future, has lent more of a sense of urgency to calls for integration and coordination. To be successful, the effort to reform the health care system as it relates to families in poverty will have to be solidly and formally connected to elements traditionally considered to be outside the purview of medical care management. Human services, called health supportive services in the "Pathways" report,[9] need to "wrap around" health services

and be quickly and readily accessible to health care providers through formal agreements.

As the "Pathways" report was being written, it became increasingly clear that a framework was needed for the effective integration of health services into the human services network. The report is being used as an advocacy tool; submitted to and discussed with the insurers, agencies, and public officials that are playing a role in the design of the managed-care system in Rochester. It is for this purpose that the "Pathways" report presents recommendations for concrete and feasible steps to create a system of coordinated health and health-support services for at-risk children and families in the city. Most of the recommendations address problems that are not unique to Rochester, and can serve as a framework for change for many communities in New York State and across the country.

Recommendations for Creating an Integrated Health and Supportive Service System

The "Pathways" report specifies what are believed to be the critical elements that should be incorporated into the health care system if it is to address the needs of impoverished, high-risk children and families. It outlines some general principles and specific recommendations. Although empirical data are not available to demonstrate the effectiveness of many of the recommended steps, the recommendations represent 2 years of interviewing and planning with service providers and leaders in Monroe County and Rochester, as well as statistical analysis and an extensive review of the literature.

Recommendations for change are organized into five categories:

- Principles for comprehensive care;
- Coordination and integration of services and funding;
- Recruitment, training, and retention of providers;
- Simplified eligibility and access;
- Monitoring of child health status and service utilization.

1. Principles for Comprehensive Care

Universal access to health insurance is a necessary, although in itself insufficient, element of health care reform. In Monroe County, because there are programs that provide health care coverage to those who cannot afford private insurance and are ineligible for Medicaid, more people have access to insurance than in many areas of the country. Child health status indicators demonstrate, however, that this is not enough. A comprehensive system of care, encompassing all health and human service programs and services related to children and women of childbearing age, is needed. That system should be based on the following principles:

- Access to services must be based upon need, rather than on the predetermined criteria of categorical programs and funding sources, and emphasis should be placed upon prevention, coordination, and continuity of care.
- Any attempt at system reform that does not take steps to address the issues surrounding cultural diversity ultimately will not succeed in reaching many of the people who need help most. This involves not only hiring staff who reflect the community being served, but also training all staff to be cognizant of the cultural values and traditions that individuals bring with them when they seek health care and supportive services.
- Any co-payments, premiums, and co-insurance charged must be in proportion to low-income budgets. Any but the most nominal co-payments for poor or near-poor families would pose a great hardship, discouraging the use of vitally important services.
- There should be no exclusion or limitations on health coverage because of pre-existing conditions.
- Support services and policies must be implemented so that potential barriers to care can be overcome. Such services and policies should include transportation services in the form of bus tokens and improved schedules and routes, availability of bilingual staff and translation services, flexible hours, and co-location of services whenever possible.
- Services such as case management and coordination of care

should be viewed as essential components of care for high-risk or multiproblem children and families, and as such must be adequately reimbursed. Other items that should be deemed essential for those that need them are mental health and substance-abuse services, family planning services, developmental assessment and intervention services, and supportive services such as home visitation.

2. Coordination and Integration of Services and Funding
   Duplication, fragmentation, and lack of coordination are increasingly recognized as serious health-service problems for at-risk children and families. The structures of the current categorical service system and the means by which both health and human services are funded make it difficult to create integrated, coordinated services. Formal ties must be created between traditional medical services and the human service sector. Co-location of services within the same facility would be ideal. Minimally, health care providers should have access to a case manager who has direct linkage to the services that are needed by families, knows the family's needs and limitations, and can fashion a package and schedule for services that takes into account the family's eligibility, as well as other concerns such as transportation and timing.

   Attempts should should be made to change the way in which health and human services are funded and managed, to better coordinate care. Initiatives to redesign service delivery systems should be supported, studied, and, if successful, applied to broader segments of the health and human-service community.

- Some needed services will require new spending at the federal, state, and local levels of government, and by private entities and insurers. Nutrition programs, mental health services, family-oriented rehabilitation programs for mothers with substance-abuse problems, and high-quality early childhood programs are among the services that need more support in Rochester and other communities across the country. In tandem with redesigning the way current resources are allocated, we must identify the services that require increased funding

and obtain the needed support. It should be recognized that short-term expenditures in these and other areas are likely to result in financial savings over time, as potentially costly problems are addressed earlier.

3. Recruitment, Training, and Retention of Providers
   Steps must be taken to appropriately train, recruit, and retain adequate numbers of primary care providers to care for high-risk youth and families.

- As part of their training, medical practitioners involved with at-risk families should receive formal exposure to other professionals and human-service agencies involved with providing services to families, to foster understanding of the roles of various agencies and to enable them to better work with the human-service providers. It would be preferable if this exposure occurred throughout training, on an ongoing basis, in community settings rather than at hospital-based clinics.
  Medical schools often are ideal for such interdisciplinary exposure and community-based educational experiences. Local community leaders and architects of health care reform should work closely with medical schools and their clinical departments to help create incentives, training tracks, and programs that will provide increased numbers of appropriately trained primary care physicians who can and are willing to work collaboratively with non-physician colleagues.
- Plans to recruit and retain primary care providers in settings where high-risk youth and families receive their care should be designed, implemented, and monitored. Efforts must be made to assure that families' needs are met and providers are able to deliver care in a setting and manner that provides them with a sense of professional accomplishment, pride, and recognition. The reimbursement system should be designed to reflect the additional workload required by providers who work with high-risk families within the managed-care system.

4. Simplified Eligibility and Access
   Women and children should have to go through the process of applying for health and related services only once, with yearly updates. They

should be able to do this by mail, at doctors' offices, or at any site where eligibility workers are stationed. The eligibility form should be short and simple, and completing a single application should determine eligibility for all relevant services.

5. Monitoring of Child Health Status and Service Utilization
Many communities are moving toward implementing Child Health Report Cards to monitor, track, and display in a simple fashion trends in a finite number of key child and family indicators. Such report cards serve three vital functions:

- They provide a mechanism to identify problems and track changes over time so that systematic, planned, community-wide strategies can be devised and implemented.
- They provide a vehicle for child advocacy which can be easily used by advocacy groups and media professionals, as well as health care planners, making it easy to capture the public's attention.
- They help focus on outcomes.

Child health report cards should be standardized across health plans. We should be able to assess and compare quality, cost, consumer satisfaction, and outcomes. A unique personal identifier should be developed and implemented for all individuals receiving services with public funding, so as to facilitate coordination of services, help identify gaps, overlaps and duplications in services, and provide unduplicated estimates of persons served, by provider, type of service, and expenditures.

Next Steps

This paper describes the process undertaken, and the recommendations made, by health and human service providers in one community to attempt to lay a framework for creating a comprehensive, needs-based health care system for impoverished and at-risk children and families. Some readers may find these recommendations to be overly ambitious; others may believe that they fall short. Both appraisals are correct, in part, for the task of bringing true change to large, entrenched and disparate systems is

daunting. This, however, is a time of great opportunity, both because of the expanding population of families at risk and because much local and national attention is focused on health care reform. We must have the will and the vision to ensure that the reform effort will bring real and constructive change for the ever-growing population of impoverished and at-risk children and families. The implementation of wide-reaching change will require the involvement of many community agencies and local officials. It would appear that local public health departments have the appropriate orientation to lead such efforts. Inner-city health care providers and "front line" human service providers also have perspectives that are imperative to the development of such an effort. In many cases, individuals in academic medical centers have capabilities that facilitate the process, such as an orientation toward research and the collection and analysis of data. In many areas of the country, those centers also are major providers of health care to the at-risk, impoverished population. The report discussed in this article is only a first step toward the development of a coordinated system of health and human services for high-risk urban children and families. In the Rochester community, ongoing efforts are being made to advocate for implementation of the report's recommendations with the local congressional delegation, with local initiatives taking place within the community, with the University of Rochester School of Medicine and Dentistry, and with other governmental and private agencies and individuals.

It is hoped that the report will bring all of these dedicated people together, to ensure that health care reform efforts do not lose sight of the growing number of impoverished families in Rochester. Similar steps can be taken in many other communities; this article can serve as an outline for those efforts. Additions and changes can be made to the report and to the Rochester community's approach; these will be welcomed as attempts are made to create both a framework for building a new system and a yardstick for measuring a community's progress toward comprehensive and coordinated services for children and families.

References

1. Children's Defense Fund. *Child Poverty Data from the 1990 Census: a CDF Research Paper.* Washington, DC, 1992:4.
2. Family Impact Seminars. *Coordination, Collaboration, Integration: Strategies for Serving Families More Effectively.* The AAMFT Research and Education Foundation, Washington, DC, 1990.
3. Keniston K. and the Carnegie Council on Children. *All Our Children: The American Family Under Pressure.* New York: Harcourt, Brace, and Jovanovich; 1977.
4. National Alliance of Business. *Corporate Action Agenda: The Business of Improving Public Education.* Washington, DC: The National Alliance of Business, 1991.
5. National Commission on Children. *Beyond Rhetoric: A New American Agenda for Children and Families.* Final Report. Washington, DC, 1991.
6. US Department of Health and Human Services. *Better Health for Our Children. Vol. I. Major Findings and Recommendations.* DHHS(PHS) No. 79-55071, 1981.
7. Schorr L. *Within Our Reach: Breaking the Cycle of Disadvantage.* New York: Doubleday; 1989.
8. Smith S. *Two Generation Program Models: A New Intervention Strategy.* Social Policy Report; Society for Research in Child Development, Volume V, Spring 1991.
9. Weitzman M, Doniger A. *Pathways to a Coordinated System of Health Care and Human Services for Children and Families in Rochester, New York.* Rochester: University of Rochester and Monroe County Health Department, 1994.